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Comments on 1115 Waiver Draft

We welcome the opportunity to provide comments on the 1115 Waiver draft application on behalf of the approximately 500 children served by the Medically Fragile, Technology Dependent (MFTD) Waiver. We would again like to remind the state that while children and adults who are technology dependent make up only a fraction of Medicaid participants, they are some of the most medically vulnerable and needy individuals in the state. Their needs could easily be overlooked, and it appears that they were in the initial draft, which failed to even include private duty shift nursing as an option for long-term services and supports (LTSS).

Comments on Section II — Eligibility

Legal Pathways to Eligibility. While it has been verbally stated that all current individuals participating in Medicaid waivers will continue to be served under the 1115 waiver, we have been unable to determine the legal pathway to eligibility for children currently in the MFTD Waiver. We would like clarification on the legal mechanism that will be used to ensure children who currently qualify for waivers under institutional deeming rules will continue to qualify under the 1115 waiver, despite family incomes that exceed standard maximums.

It is critical that children from middle class families remain eligible for services because private insurance typically does not—and is not required to—cover private duty

nursing and other essential services these children need to avoid institutionalization. On average, children in the MFTD Waiver cost Medicaid $188,210 per year, and $102,062 of this amount (54%) is for private duty nursing care.[1] Even a family earning 1500% FPL with private insurance would be unable to pay for private duty nursing out-of-pocket.[2] These children cannot be cared for at home without receiving Medicaid wrap-around coverage, and most would have to be hospitalized—at three times the cost to the Medicaid program.

The list of eligible persons from the draft application (pp. 7-8) contains several designations that could include children with medical technology, including Disabled persons in 209(b) states, HCBS waiver enrollees eligible under institutional rules, and Medically Needy children. The most narrowly restricted legal pathway is to request a waiver allowing the use of institutional income rules; however, the state is not asking for said waiver in Section XI. Please clarify the rules for eligibility, and the legal mechanism used to grant this access.

Comments on Section III — Benefits

EPSDT. We have been assured verbally that EPSDT services will be maintained, and that EPSDT services will not be subject to maximums or limits under the requested waiver of amount/duration/scope rules. However, this is not explicitly mentioned in the draft application. In fact, EPSDT is only mentioned once in passing. We would prefer written assurance within the waiver application itself that all EPSDT services will be available to children without limits or maximums.

[1] 2010 data. Data from http://www.hfs.illinois.gov/assets/090811_ccmn_ncps.pdf and http://www.hfs.illinois.gov/assets/ccmn_facesheet_history.pdf

[2] See http://savemftdwaiver.com/incomecaps.html for the financial breakdown and calculations.

Comments on Pathway 1 — Health Care Delivery System

Managed Care. Currently, children in the MFTD Waiver have been excluded from ACOs and CCEs because many children in the program have private insurance and only use Medicaid as wrap-around coverage. In addition, most children in the MFTD Waiver require specialized services that typically cannot be delivered within one health care institution or program, which is difficult to accomplish within the structure of an ACO or CCE. We request that these children continue to be excluded from managed care, and only provided care coordination services.

Telemedicine and Home Visiting. We also encourage the state to consider expansion of telemedicine and visiting nursing services to children with complex medical needs. As we cited in previous recommendations, adding these components in a similar program in Boston resulted in substantial savings.[3]

Other Innovations. We also encourage the state to consider the additional proposals we have put forth in the past, including a robust care coordination program, emergency response visiting program, a funded concurrent palliative care option, and a DME loan/maintenance program.

Comments on Pathway 3 — Health Care Workforce

Nurse Training Program. We would like to see a training, evaluation, and competency program created for home health nurses in Illinois, and to see nurses paid a competitive wage. Not only has the state failed to increase the private duty nursing reimbursement rate for more than a decade, but the legislature actually *reduced* the rate 2.7% in 2012. Because Medicaid does not pay nurses a competitive wage, cases are often staffed with incompetent, poorly trained nurses who have failed in clinical settings.

[3] http://savemftdwaiver.com/reports/costcutting.pdf

The practice of nursing in the home care environment differs considerably from nursing in a clinical setting. Nurses must be able to act independently without having immediate oversight, they must learn skills (such as ventilator care and maintenance) that are not typically performed by nurses in hospitals, and they must also learn how to provide services within the context of a family environment. Illinois needs to invest in nurse training specifically for the growing home care market to ensure an adequate supply of appropriately trained and qualified home care nurses.

In addition, home care nurses in Illinois are not unionized, and therefore cannot receive benefits or liability insurance without working for an agency, which presents problems for a budget-based consumer-directed service model. We suggest the state consider creating a statewide network of home care nurses that would allow nurses to become independent contractors and work directly for families, in the same way personal care attendants currently are handled by the state.

Comments on Pathway 4 — LTSS

Private Duty Shift Nursing. We are extremely concerned that private duty shift nursing is not listed as an LTSS option. While we were verbally told this was an oversight, private duty shift nursing absolutely must be included in the final draft, or the state will fall counter to the current settlement decree for the Olmstead case *Hampe v. Hamos*. In addition, this represents a service reduction that introduces a further institutional bias for individuals who are technology dependent. While children may be shielded from these reductions by EPSDT, adults lack such protections, and will only be able to access nursing care through an institutional setting. The current definition for skilled nursing (pp. 71-2) restricts individuals to 365 hours per year, an amount that is

inadequate for adults who have aged out of the MFTD waiver but still require daily shift nursing to manage critical medical technology.

Assessment Tools. We continue to have concerns about the universal assessment tool being based on functional abilities, which are not easily measurable in developing children. We encourage the state to consider maintaining a separate assessment tool for children, and specifically for children on medical technology.

EPSDT. We would like assurance that budget-based plans and assigned service tiers will in no way be used to reduce or limit EPSDT services that have been prescribed by a physician as part of a treatment plan.

Waiting Lists. The request for a waiver of reasonable promptness (p. 48) seems to indicate that waiting lists will become a part of this program. While the draft application discusses the current waiting lists for individuals with developmental disabilities, it does not mention how new applicants with serious medical issues, such as newborn children on ventilators, will be placed on waiting lists. We would like clarification as to whether all children who are presumptively eligible for the program will be afforded immediate access to the program, and if not, what type of system will be used to prioritize access. We continue to encourage a system of reserved spots for children with medical technology to ensure access is always available. We also want to guarantee that the wider eligibility pool of both children and adults will not impact the ability of children on medical technology to obtain urgently needed services without delay.